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Treading on Eggshells: ‘Doing’ Feminism in Educational Research

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Abstract

This paper explores the contradictions of ‘doing’ feminist research, and how the materiality of engaging in fieldwork magnifies the gap between ‘ideal’ versus ‘actual’ feminist ways of conducting research. Drawing on my Doctoral research with British-Pakistani mothers of children with SEND, I explore the ethical, and methodological challenges of engaging with feminist methodology and how this contributes value to the research process when working with marginalised groups. I examine three principles of undertaking feminist methodology; firstly, the ethical challenges arising from conducting unstructured interviews in a non-therapeutic context with vulnerable participants. Secondly, I explore how feminist researchers can positively contribute to making practical difference in the lives of the women they research with, thereby going beyond how feminist values of reciprocity and responsibility towards participants have traditionally been implemented in the field. Finally, I consider utilising theoretical frameworks which help analyse data to reveal sites for social change. This paper concludes by noting that traditional feminist methods may not always be more ethical, and that as feminist researchers we must be willing to adopt a holistic view of feminist values, where the vulnerabilities of the researcher and participants are both respected and where methodology is adjusted accordingly.

Keywords: Feminist methods, interviewing women, Intersectionality, consciousness-raising, marginalised groups

Introduction

Feminist methodology offers one of the most engaging and grounded ways of doing ethical research that is an active site for social transformation. Early feminist epistemology was developed to challenge existing ways of knowledge production. Lennon and Whitford (1994) state that previously, claims to knowledge were not only masculine but also reinforced power over other groups by systematically silencing other ways of knowing. Arguably, the objective lens was the historically dominant way of knowing and arriving at a single truth, employing transparent scientific methods that separated the seeker from the field. Traditional feminist methodology grew as a response to the need to push back against the masculinity of knowledge production, by developing a more reflexive view of reality and truths. Early feminist methodology focused on qualitative research and proposed the positivist paradigm sought and legitimised only partial truths, limiting reality to the measurable and quantifiable which dismissed the significance of experienceable realities. Feminist epistemologists did not discredit the scientific method altogether, rather viewed it as ‘bad’ science which only served masculine interests. Harding (1987) diverged from a qualitative subjective focus, and posited three main strands of feminist epistemology underpinning more ethical research methods: empiricism, standpoint, and postmodernism.

Until the early-1960s, Olesen (2000) suggests feminist scholarship had focused on women’s subjective experiences, their relationships and roles that were organised through a “*social process of socialisation*” (Smith 1987, 26). For instance, Griffith and Smith’s (2005) study found that schooling policy and practice based on stylised middle-class mothering reinforces social inequality, supporting neoliberal policies which place the full responsibility of children upon mothers. This departure from a reactive “*unremitting whiteness in feminist research*” (Olesen

2000, 219) was raised by Davis (1981), Collins (1986), Asch and Fine (1992), and others who challenged the exclusiveness of the 'knowledge' characterising mainstream feminist thought. Feminist academics also highlighted the need for different kinds of 'knowledge' because oppression, representation, and agency is influenced by the intersection of various social divisions (Crenshaw 1991). Since then, feminist epistemological and methodological scholarship has become more inclusive, recognising varying intersecting contexts focused on giving privilege to women's voices; however, there is no unequivocal definition of what being a feminist researcher entails. Based on their own practical field research experiences, feminists from different disciplines have developed their own 'guidelines' or 'ideals' for employing feminist methodology; this has helped other researchers keen to engage in feminist research methods. Cook and Fonow (1986) suggested five key principles of feminist methodology within sociology. The first principle entails the researcher addressing the gender asymmetry that characterises all lived experiences. Secondly, that the methodology is 'consciousness-raising', employing appropriate methods and analysis. Thirdly, that the feminist methodology should address the subjective experience and acknowledge the power dynamics which exist between the researcher and participants. Fourthly was consideration of ethical implications of researching women, and using their private experiences for public discourses. The final principle was emphasising the empowerment of women through the research process, giving them agency to challenge oppressive structures. Cook and Fonow's (1986) tenets provide a valuable introduction for feminist researchers who are dissatisfied with how existing research has excluded women's voices. For instance, home-school literature has long ignored the gendered nature of parenting a child, excluding maternal concerns and experiences within the discourse of improving home-school relationships; however, this gender asymmetry has shifted recently with more feminist researchers reporting maternal

perspectives. Cook and Fonow (1986) suggest that feminist research must be focussed on women's experiences, however, this principle risks homogenising the experiences of all women without consideration of the intersections with other social divisions. Therefore, academics researching women from marginalised ethnic groups may require an intersectional lens to conduct consciousness-raising and transformative research.

Following Cook and Fonow's (1986) seminal research, Bloom and Sawin (2009) have posited their own framework for evaluating research practices, characterised by five main ideals: (1) All feminist research should be focused on women's voices and experiences, and reducing the power asymmetry between the researcher and participants; (2) Analysing data to uncover sites of resistance and opportunities for social change; (3) Creating a practical difference with the women we study; (4) Doing research that affects and challenges social policy; and (5) Doing research that improves our own reflexivity in becoming catalysts for social change. Bloom and Sawin's (2009) framework holds considerable significance for researching women from diverse backgrounds, because it questions traditional feminist methods over whether giving voice to women is enough. It emphasises the researcher's own relationship to the field and her role towards those oppressive structures that situate the researched. The researcher is not only a conduit for consciousness-raising and bringing about social change, but must also recognise that her frames of reference and worldviews may not always be compatible with her participants (Gorelick 1996). This permits feminist researchers to transcend traditional means of analysing data, exploring more ethical data analysis techniques which consider the participants' and the researcher's own explanations and in doing so revealing sites for social change. Moreover, Bloom and Sawin (2009) posit that feminist researchers *need* to do more *activist-oriented* research that creates a practical difference for the women they research with. This extends beyond traditional feminist protocols of reciprocity,

respect, and responsibility, towards a stance that addresses the researcher's privilege in the field. Bloom and Sawin (2009) consider that this reinforces Brantlinger's (2003) notion of 'social reciprocity morality', which challenges researchers not just to theoretically explore issues of social justice but to practically realise egalitarian goals. Implementing this ideal can be complicated because the research process itself can be imperfect, limited by financial and time factors. Rather than merely involving participants as co-researchers, these ideals compel researchers to think more creatively about how they can use their social and material positioning to benefit the women they research with. These methodological frameworks discussed have provided feminist researchers with a general template to work and further refine in their own research, disregarding features inappropriate to *doing* feminism in the field.

This paper draws from own experiences of researching with British-Pakistani mothers of children with Special Educational Needs and/or Disabilities (SEND) for my Doctoral thesis. I adopted feminist-informed research methods and theoretical perspectives in order to more ethically represent these mothers' views. In line with the discussions above, I deliberated over the challenges and dilemmas of implementing a feminist-informed methodology within my research, and building on existing literature regarding the appropriateness of using feminist methods with minority and marginalised women. I explored three particular areas of contention: (1) Using consciousness-raising methods and data analysis; (2) Making a practical difference with the women I research with; and (3) Analysing data to uncover sites of resistance and opportunities for social change.

The Current Study

My research examined British-Pakistani mothers' experiences of supporting their children with SEND, an acutely under-researched area from an education perspective. I explored maternal

perceptions of their relationship with their child's school, the roles of mainstream and special schools in their child's education, and their placement preferences. I also sought to understand how religion, culture, gender, and immigrant history all affected maternal experiences of using SEND provisions to care for their child, highlighting their experiences as a minority within a minority in relation to UK SEN provisions.

There is a higher and increasing prevalence of Profound Multiple Learning Difficulties (PMLD) amongst British-Pakistani and British-Bangladeshi families compared to other ethnic groups (Strand and Lindsay 2009; Emerson 2009); some studies suggest they are three times more likely to have severe disabilities (Hatton et al. 2004). The rise in severe disabilities within these ethnic groups has been attributed to consanguinity and material deprivation; the Institute of Race Relations (2015) found that British-Pakistanis and British-Bangladeshis were the most likely ethnic groups to be living in persistent poverty, with nearly three-quarters of 7-year-olds from these communities living in poverty. Over recent decades, several key studies have researched disabled families' experiences of special education (Shah 1995; Kalyanpur, Harry, and Skrtic 2000; Hess, Molina, and Kozleski 2006), and have advocated for disability research to be more representative of all ethnic-minority experiences. Despite this, research into ethnic-minority family experiences of disability can often be reduced to cultural and language barriers. Moreover, Garcia and Ortiz (2013) found that minority research generally can be homogenous, habitually recommending that professionals acquire cultural competencies and using professional interpreters when interacting with minority families. Therefore, special education research and practice needs to consider the complex and constantly-shifting contexts influencing how disability is experienced by ethnic-minorities (Garcia and Ortiz 2013). My research reinforces Garcia and Ortiz's stance on the need for an intersectional lens when researching with diverse families.

My qualitative research sampled eight British-Pakistani mothers in Southwest England. I accessed participants through a disability support group for South Asian families, and through ‘snowballing’. I closely followed my university’s ethical guidelines, attaining the ethics committee’s approval prior to commencing data collection. I eschewed one-off participant consent, opting instead for an ongoing consent process which ensured mothers knew they could withdraw from the research at any time. My methodological aim was to be inclusive and reflexive.

Using Consciousness-raising Methods

After deliberation, I chose to conduct in-depth unstructured timeline interviews as an initial data collection tool, because it would help develop interview questions for semi-structured interviews and vignettes in subsequent data collection phases. Unstructured interviewing reflects postmodernist, feminist and inclusive aims in wanting to understand the historical and situational factors influencing knowledge production, promoting diverse perspectives and making research more dialogical. Campbell et al. (2010) suggest that feminist interviewing incorporates three main features: (1) Reduces power asymmetry between the researcher and participants; the interview format facilitates structural flexibility, promoting mutual dialogue and permitting interviewees to decide what story to tell and how to tell it. (2) Enables participants to normalise their experiences and discuss them in a safe environment. Traditional structured interviews do not give space to women to share personal experiences significant to them and which need to be included within mainstream research. Oakley (1981, 48) suggests that departing from the masculine paradigm of interviewing would bring the experiences of women “in sociology but more importantly in society” to the fore. (3) Unstructured interviews recognise the emotional demands of being interviewed; participants may experience moments of anger, grief and laughter whilst sharing their most

intimate and vulnerable moments. Unstructured interviews provide participants the space to experience and validate those emotions rather than automatically moving onto the next question.

I also chose unstructured interviews as my first data collection tool because I did not know my participants; I wanted to start with an open conversation without assumptions about their lives, choices and experiences. Moreover, my research discussed complex sensitive topics; mothers were expected to share personal views and experiences around mothering, disability, child bereavement, pregnancy, religio-cultural views and any topic they considered relevant. Rather than capture unguarded conversations, I wanted to give mothers a conscious flexible choice to discuss events they felt comfortable disclosing, providing privacy with the freedom to disclose information as they wanted. I also developed my semi-structured interview questions and the vignettes from the data collected from each mother's unstructured interview, to help explore how broader factors affected their daily lived experiences.

All mothers agreed for interviews to be audio-recorded, with assurances that these recordings would be deleted post-research. Mothers were given copies of interview transcriptions, with the opportunity to contribute to the research analysis if they wished. During the unstructured interviews, mothers disclosed their pre-natal and post-natal experiences, their personal backgrounds, whether they were first-time parents, and their experiences during their child's SEND diagnosis. All mothers were extremely emotional when describing the very painful events and experiences around their child's diagnosis. I was careful to pause or even stop interviews if mothers were visibly upset, and only resumed if and when they were okay. Some mothers continued discussing distressing events, however, I also changed topics to give mothers some emotional respite.

Most mothers expressed the positive aspects that emerged from participating in the interviews. However, one mother, Kiran¹ revealed how emotionally stressful her unstructured interview had been; her experiences were deeply troubling because I had tried to make the interviews sensitive to my participants' needs. Kiran had one child, 15-year-old Ahmed who had global developmental delay. I realised in our first meeting that she was reserved; unlike some mothers who didn't need prompting, Kiran required specificity in my questioning to garner a response. This was difficult in an unstructured interview that depended on Kiran to take the lead. She cried at various points during our conversation, particularly when she shared concerns for Ahmed.

Kiran: As he's getting older...I'm going to get really emotional about this because me and my husband are always thinking about what's going to happen to him when both of us pass away...because he's never going to be able to live by himself. Nothing's going to be the same for him. But what's going to happen with him? Obviously, we don't want him in assisted living while we're still here...but we're not here forever are we? [Crying] Yeah, so that's our concern.

Kiran also broke down towards the end of the interview, when I asked her to elaborate on how she supported Ahmed.

Kiran: It took me a long time to get over it [realising Ahmed had SEND] because I had a healthy pregnancy. I did go through the emotional *why us? Why him? Why me?* Because I don't drink, I don't smoke, I don't take drugs...[crying] When you think of all those women who take drugs during pregnancy and they have healthy babies...it took me a long time to get over that emotionally.

¹ All participants' names are fictitious to protect their anonymity and confidentiality.

The second and third interviews were semi-structured and were generally less emotional, discussing school roles and responsibilities and their experiences of working with their child's school. When I concluded each interview, I asked each mother for her feedback on the interview process, and whether there were aspects that I had missed. I asked Kiran if she had felt uncomfortable during the interviews,

Kiran: Well, a disadvantage, going through all those painful memories again, because the first [unstructured] interview was really quite emotional for me.

Kiran: Oh my God, where have those 15 years gone?...at Easter at my mum's, Ahmed insisted on pulling my suitcase, I was saying, *No, I'll do that*. Afterwards I thought, if he was an able-bodied 15-year-old, I wouldn't have said *No*. All these little things...wishing he was a normal able-bodied 15-year-old, but he's not.

During our exit conversation, Kiran revealed that the interviews had dredged-up painful memories, with the realisation that even after so many years she still wished for Ahmed to be 'normal'. This was unsettling because I specifically chosen to conduct unstructured interviews to de-privilege the researcher's voice, promote inclusiveness, and allow mothers to choose what they wanted to disclose. I had not anticipated that the absence of impersonal interview questions (as found in structured and semi-structured interviews), would magnify my participants' vulnerabilities. This recalls Sikes' (2006) past experiences as a teenager of participating in a postgraduate study on the effects of films on young people. Researchers had shown horrific footage of Nazi concentration camps, leaving a friend of Sikes feeling traumatised and withdrawing from school. Whilst my own research did not cause such extreme trauma, I did question whether the unstructured interview had been worth Kiran's tears. More worryingly, my own role in her distress exposed how "dodgy" (Sikes 2006, 112) some stages within my research journey had been, questioning whether engaging

in this narrative-style of interview was ethical. Kiran had had to recall painful memories before she was ready, demonstrating that research tools designed to promote participant autonomy can have an emotional price. I apologised and assured Kiran that the distress caused was entirely unintentional, however, I felt my apology was inadequate because I could not undo the hurt caused. Ultimately, all mothers confirmed that they were glad to have participated, however, the interviews served different purposes to different mothers. For some, I was a non-judgemental ‘friend’; to others, my interviews informed them about different provisions available, or enlightened them about various service providers.

For Saira, unstructured interviews provided her a safe space to reassess her past actions, and empower her to take charge of her children’s future. My interview with Saira was initially about her youngest daughter, six-year-old Zara who has attention issues. I quickly realised that Saira had two other children aged 15 and 19 years who had mental health needs; therefore, we discussed each of them at equal length for the remainder of the conversation. During the unstructured interview, Saira disclosed her son, 19-year-old Faraz had been excluded firstly from mainstream school and then from special school because he refused to take his ADHD medication. Thereafter, he was home-schooled and the council sent a teacher to his home once a week.

Saira: All Faraz insisted was, *give me a chance to prove myself in mainstream school*...but the answer was always no, he said he just couldn’t take it in that school...and as it’s his right to get educated, they found him a home-tutor. I feel Faraz just slipped the net because the teacher only came once a week for about two hours...that didn’t help.

During the second interview, Saira disclosed her 15-year-old daughter, Farha had depression and refused to attend mainstream school. The school complained about her truancy and threatened

Saira with court action, however, after Saira involved an intervention worker the school dropped the complaint and became supportive of Farha's needs; they decided that Farha should attend an early college. Saira became anxious because Farha had struggled within mainstream school and could not be expected to cope with college. During my second interview, I suggested that since Faraz had gotten a home-tutor, she should also request one for Farha through her social worker.

Saira: They [the school] haven't given me anything...If she's not coming to school they should've said something...I could take this back to them. What they've suggested is we put her into early college. But if she's not coming to school, how will she go to early college?

Me: Could you consider a home-tutor, you know you mentioned that Faraz had had one who helped him catch up with school...can you ask one for Farha?

Saira: I could ask for a home tutor...That completely slipped my mind! That'll solve my case. If they could give me a home-tutor to come home to teach her ...she should be entitled to an education. Glad I came today [laughter].

Subsequently, Saira requested a home-tutor for Farha from the school and changed their decision about Farha attending college. This spontaneous interactive development during interview only arose because I had conducted an unstructured interview, which had allowed Saira to share her experiences of Faraz with me. As with all my participants, I asked how Saira felt towards the process of interviewing.

Saira: I realised I've got more choices out there with my daughters going to school...I didn't realise I could demand this [home tutor] since she wasn't Statemended, that I could demand homework...so from the interview I learned that I could request and that I'd get

it. So I benefited from that...It's changed my way of thinking, made me think more in-depth about my children's education...it's made me more assertive.

Although I have shared only two examples from my interviews, nonetheless, they highlight the risks and the benefits of conducting in-depth unstructured interviews. Although seven out of eight participants did not express any distress from the interview process, the fact that one mother did experience distress raises methodological, ethical, and theoretical questions regarding the utility of unstructured interviews as well as my role as a non-passive interviewer. Therefore, further examination is required as to how the process of conducting in-depth interviews in a non-therapeutic context can be improved.

Making a Practical Difference

Although I had my university's ethical guidelines as a reference to best practice, nonetheless, I encountered many ethical dilemmas within my research which had no set reference, which I had to extemporaneously resolve. As a feminist researcher, I struggled with how to respond and make a practical difference to those women who had asked me for help in non-research related matters, because there were no ethical codes I could refer to within feminist methodology. Dismissing their concerns or merely signposting them to relevant services for guidance would have reinforced the notion that, as researchers we engage in fake rapport and that our 'relationship' extends only as far as our research requirements. As a full-time Doctoral student with my own mothering responsibilities, the advice from the well-intentioned academic community is to keep my distance and only help my participants if it does not hinder my already time-constrained schedule. I found this very confining and frustrating, and I gradually distanced myself from this rigid ethical framework towards one that was situated within the field. It was reassuring that other women researchers had previously faced similar dilemmas; merely *"laughing off the request with remark*

that ‘my job at the moment is to get opinions, not to have them ’’ (Selltiz et al. 1965 [cited in Oakley 1981, 48]) would have stifled a participant’s concerns, and would be antithetical to feminist goals. In her research with expectant first-time mothers, Oakley (1981) reported receiving information requests from participants about medical procedures, baby care, and human reproduction. Whilst she did not possess the expertise to comply with every information request, nonetheless, she found it natural to become personally involved in participants’ lives after her prolonged engagement. I found it equally difficult to navigate such delicate terrain; as a ‘*didi*’ (sister) or a ‘*beti*’ (daughter) to my participants, our collective ethno-cultural and religious identity added another layer of attachment and obligation in addition to our shared gender. Whilst I felt privileged to be considered a part of my participants’ lives, I also acknowledged my duty to maintain their trust and to help them wherever possible. For instance, before arranging an interview date I met one participant, Tahira at her home to introduce myself face-to-face and discuss her participation. As I finished our discussion, she requested help in a non-research matter; she was the sole carer for her child with SEND (and two non-disabled children), as well as her husband who is also learning-disabled and her aging in-laws. It was clear that her in-laws were emotionally unsupportive of her needs, and were only concerned with her role as their carer. In their absence during our meeting, she confided that she needed greater independence to care for her family in the way she wanted; she wanted to learn English to help in her everyday life, and learn to drive, but was not confident that her local support group would keep her request private and so she did not know who else to approach. She was dependent on her father-in-law to drive her around which was awkward for her. I felt that I could not simply point her to a person she *should* approach, because she had directly asked for my help in confidence; moreover, she had expressed lack of trust in her support group. Therefore, I assured her that I would help. I contacted the LA about her

situation and enquired about English classes within walking distance of her home which took place during her children's school hours. The council suggested two language centres fulfilling these criteria which were free of cost to local residents, which I forwarded onto Tahira. This direct intervention on my part as a researcher, resulted in a small yet significant change for my participant, and taught me an invaluable lesson about adopting a more sensitive and mindful stance in the field. Such impromptu encounters awakened my ethical responsibility towards my participants in non-research matters.

In another instance, Tahira confided that she needed a confidante who also had a child with SEND who could offer her advice on occasion. I informed her about another participant who was a first-generation immigrant like her, who possessed a lot of experience of getting the right support for her child with SEND. After Tahira's assent, I approached Parveen, my other participant to gauge if she was willing to befriend and mentor Tahira. At this point, I did consider the ethical implications of breaching the confidentiality and anonymity of both participants, but I had decided to prioritise participant needs over my university's ethics code. I rationalised this decision as my engagement with social reciprocity morality where my actions were governed by what was morally fitting for my participants, since I was committed to achieving egalitarian goals. Moreover, since both participants had consented to sharing their contact details, I was confident that I was not betraying my participants' trust or putting them in danger.

I also helped another participant, Alina to find a befriender for her son, Imran who had autism. Alina was willing to provide VBA therapy training to the appropriate person, and asked if I knew anyone at my university who would be interested in this job. In response, I designed posters advertising the job and put them up across my university campus, and also advertised on social media; as a direct result, Alina found a suitable person within a week. Alina also asked me how I

could help strengthen her case for Imran's provision with the LA. Imran's existing rate for care and mobility was insufficient to ensure his day-to-day care, so she asked for my help in drafting an appeal letter to the council to provide Imran a higher rate for care and mobility; Alina's previous application to raise the rate had been denied by the LA. She provided various documents including her previous letters to the council to enable me to frame a strong appeal; ultimately, she succeeded in securing better provisions. As I increased my involvement with Alina, again I did not feel it was inappropriate; on the contrary, had I not helped Alina, I would have questioned my ethical responsibility towards my participants.

Analysing Data to Uncover Sites of Resistance and Opportunities for Social Change

Within feminist research, data analysis should not only reveal sites of transformation but also ensure that the researcher's and participants' worldviews are equally recognised and validated, even if they are incompatible at times. Adopting Weber's (2001) Intersectional Framework allowed me to evaluate what constituted research which was relevant to, and would empower an already overly-researched, disadvantaged and discriminated community. I utilised the Intersectional Framework to reinforce my feminist stance within my methodology, and to explore maternal experiences situated within simultaneously-occurring contexts which had previously been overlooked within literature. This was challenging because there were no guidelines on how to apply this framework within qualitative research. In fact, the only other qualitative study to employ Weber's (2001) Intersectional Framework was by Björnsdóttir and Traustadottir (2010), an Icelandic study using life history to examine how disabled individuals experienced disability within the broader context of social inequalities. They based their data collection on the five categories highlighted by Weber (2001). However, I found the benefit of utilising Weber's

Framework went beyond how to merely collect data, but rather it highlighted how I *should* research mothering within a minority context.

I am reminded of Smith's (1999, 198) query to researchers who study indigenous communities: "How can research ever address our needs as indigenous people if our questions are never taken seriously?". As a researcher who broadly shares the same British South Asian category as my participants, conducting my research has strengthened my position on the importance of promoting enabling discourses, and voicing the questions that the community is asking rather than dismissing them. Academics who are passionate about researching disadvantaged and marginalised communities have asked: 'Is disability too White?' (Thompson 2016). This entails researchers like myself deconstructing how South Asian Muslims are discussed and situated in the current climate where Islam is deeply problematised, and discussing the positive role that religion can play in the experiences of British South Asian Muslim disabled families. This framework proposes that social divisions and categories constantly change and interact with the actors, influencing their positioning (Staunæs 2003). Therefore, I examined how historic and social constructs of motherhood, parental involvement, disability, inclusive education, and ethnicity have all evolved and how the actors identify with these constructs. I also fused and interlocked social divisions with an individual's identity and experiences, which produced a holistic experience. For instance, a British South Asian mother of child with SEND cannot separate from her experiences as a British South Asian *Muslim* mother of child with SEND. Weber's intersectional approach posits that social divisions are experienced simultaneously, so that actors can occupy dominant positions within one experience but a subordinate position in another. This provides hope that oppressed populations may not be oppressed in all aspects of their lives, and by recognising how social divisions can create disadvantage, they can advocate for a more equitable position.

British-Pakistanis have the highest incidences of consanguinity (between first-cousins and second-cousins) amongst any ethnic group (Darr 2009). This has also been highlighted in the media:

Asian community 'in denial' over inbreeding - MP (The Yorkshire Post, February 11, 2008)

Bradford is 'very inbred': Muslim outrage as professor warns first-cousin marriages increase risk of birth defects (Kelly, Daily Mail, May 30, 2011)

There is a perception that South Asian Muslims reject genetic counselling and prenatal testing because of their religious views, however, this has been contested by existing research. Mothers in my study also expressed overwhelming frustration with the stigmatising of consanguinity within and outside the South Asian community, and its link to their child's SEND. Many mothers reported that this was often the first question they were asked by medical and other professionals.

Maria: He's got this condition that doctors told me...[I] had first-cousin marriage...which I understand caused not just this but any condition...I don't see him [Aamir] just as a condition that's labelled on him.

Interestingly, Maria's interview revealed her sense of double consciousness (DuBois 1897); she acknowledged that some professionals viewed the consanguineous nature of her marriage as the cause of her child's SEND. In fact, she also recognised that children from cousin marriages also had increased chances of inheriting their parents' other genetic characteristics such as a tendency towards heart disease, diabetes, and cancer. Existing health studies have found that male gatekeepers within families often restrict information about the risks related to cousin marriages, and that women and extended families are not made aware of the inherent risks (Darr et al. 2013). Significantly, mothers in my research who did discuss cousin marriages were not only aware of

the inherent risks, but also expressed how difficult the decision had been to have children because it affected their future family planning. It was not simply a case of knowing the risks and then making a medically-informed decision; a few mothers had to decide whether to have another child knowing they already have one child with SEND. Maria revealed that she not only received genetic counselling, but was also asked by medical professionals to consider an abortion once tests confirmed her foetus had a genetic condition.

Maria: [Medical professionals said] if the tests confirm the condition...you have to be prepared to abort the pregnancy. I said I won't do that...we're going to accept her regardless of whether she has a condition or not. They said...at the end of the day it's your choice.

Maria's reproductive plans and practices became active sites of resistance and conflicting interests, between medical experts who advised that she terminate an unhealthy foetus and her own views regarding mothering. Whilst she was aware that some may view her decision to continue her pregnancy whilst knowing the risks as careless or even selfish, nonetheless, she argued that she had unconditional love for her child and that she was prepared to do everything to support her child's SEND. Her stance was possibly her attempt to understand what mothering a child entailed, and that SEND was merely one aspect of her child rather than the defining marker. This episode also demonstrated how she was critically engaged with her own choices as a woman freely exercising her rights to reproduction, and her stance on having a child with SEND. Maria's feminist and disability perspectives are not at odds with each other; however, it is difficult to ascertain whether religious influences affected her decision to keep her baby, because Islam prohibits abortion unless the pregnancy endangers the mother's life. Nonetheless, Maria's

experience exemplifies how complex such decisions can be in the context of cousin marriages, and how these decisions may be perceived by professionals.

Cole's (2007) research with mothers of children with SEND illustrates the dangerous medicalisation of children through 'special structures', and the "medicalization of mothers and all aspects of motherhood through increasing control by medical and quasi-medical experts" (169). However, my research reveals that the medicalisation of mothers starts before mothers even decide on *becoming* mothers, since it is intricately tied to their cultural practices. Stigmatising by professionals, as Smith (1987, 19) suggests, "does not arise spontaneously; it is manufactured" to fit broader disabling discourses around South Asian communities. Other mothers in my study suggested that since they were already married to their cousins (through arranged marriages), they had to make the most of the very limited family planning choices available to them. Parveen, who was a Muslim clergywoman, suggested that cousin marriage was a cultural practice which had often been endorsed through a religious lens, although it had no religious roots; this made it harder for women to make informed choices about their body and future family planning.

Parveen: [I had] a first-cousin marriage...I'm bringing this into my sermons...cousin marriages are allowed but not obligatory...Where does it say you should only marry your cousins? Fine, it's not haram [forbidden], but cousin marriage is happening so much now. Why do you want to cause problems for your kids?

Notably, Parveen did state that abortion was un-Islamic, however, she also stressed that the prevalence of SEND within the South Asian community went beyond religious jurisprudence regarding abortion. She advocated that cultural marital practices such as cousin marriage needed to be stopped by the community as a whole to mitigate the risk of genetic disorders occurring.

Shaw (2001) found that the British-Pakistani and British-Bangladeshi communities had used close-kin marriages as an immigration strategy to strengthen their diaspora communities, and that male family members were often at the forefront of this decision-making process. This finding was replicated within my research, both for British-born mothers who married their cousins from Pakistan, as well as Pakistani-born mothers who married their British-Pakistani cousins. An unintended consequence of this practice was that the women's reproductive practices became sites of scrutiny in terms of their 'efficiency' in expanding and strengthening their diaspora communities. Parveen criticised how cousin marriages often disadvantaged South Asian women, because they not only experienced the cultural pressure to produce healthy offspring that maintained the family name, but they also overwhelmingly had to become full-time carers for their children which halted any personal or career aspirations. Moreover, they became vulnerable to further scrutiny from family and community members if their child was diagnosed with SEND; for instance, Maria related how her mother-in-law had initially blamed her for Aamir's SEND. Parveen was also critical that such patriarchal family structures were continually and erroneously promoted through a religious lens, which many South Asian Muslim families failed to recognise. She advocated for a preventative alternative, recommending that the next generation of British-Pakistanis marry outside the extended family. Sharp and Earle (2002) suggest that regardless of whether women choose to bear a child with SEND or terminate their pregnancy, they are still judged by others and their actions can still be perceived as immoral and selfish.

Utilising Weber's (2001) Intersectional Framework helped me challenge the negative imagery of British-Pakistani mothers as passive participants in their child's special educational experiences, because mothers in my research actively reconstructed their own narratives. They revealed positionings which were enabling to their experiences and social divisions which disempowered

them. Religion was not only a social signifier for mothers in my study, but it also provided a framework to help some mothers understand their experiences of caring for their child with SEND. Their religious identity did not prevent them from seeking medical or educational interventions, nor did they believe that their child would be miraculously ‘cured’ through prayer. Instead, religion provided the mothers with an alternative lens to the traditional grieving model, shifting their focus from coping to becoming resilient. In addition, their religious identity and knowledge equipped the mothers to challenge disabling cultural and community practices such as mother-blaming. Mothers did not impose religious duties on their child, but they did challenge their child’s exclusion from participating in religious events.

Maternal responses also reflected that mothers desired equal access to educational and employment opportunities for their sons and daughters. However, a few mothers also highlighted how their placement decisions had been unduly affected by patriarchal members of their extended family. Nonetheless, notwithstanding this patriarchy, I posit that mothers in my study acted as “agents of change” (Bhatti 1999, 86) within their families because they challenged traditional family decision-making and patriarchal decision-makers. Many mothers also recognised that there was cultural pressure from within the community to arrange early marriages for girls, but since their child had SEND they could escape such pressure.

Can feminist methodology work in the field?

This paper has considered the three main challenges that I encountered in implementing feminist research principles. It would be antithetical to its own objectives of critical reflection to state that feminist research methodology is a naturally, ethically, and morally superior methodology compared to all other methodologies. There is a danger that methods developed within a Western notion of gender can be dismissive and oppressive to minority groups; this was my experience

when utilising unstructured interviewing, which has been designed to promote agency and reduce power asymmetry between the researcher and the researched. My interview with Kiran exposed the deficiencies of using unstructured interviews in a non-therapeutic context. I was not a counsellor nor did she ask for my help; the interview left myself but especially Kiran emotionally exposed. Whilst I had ensured that I followed ethics protocols in leaving the field, I became critical of my own role in empowering/disempowering my participants. In retrospect, I would still ultimately have conducted unstructured interviews but perhaps considered semi-structured interviews first, before moving onto an unstructured space. I could not have anticipated my participant's reactions before entering the field, but in the process of interviewing I realised that the method itself could affect my participant's sense of self-preservation. When revealing their insecurities and their worst moments of mothering, every word is spoken aloud and cannot be taken back. Therefore, the feminist researcher must be prepared for all consequences, including triggering the re-living of an emotional trauma within participants.

I also posit that feminism is situated in the lived experiences of women, and in examining morality as it exists within inter-personal relationships. As women researchers working with women from minority and marginalised groups, this requires reconsidering how our research and our relationship can positively and practically impact our participants. We must recognise that participants may not see the value of how our research is contributing to the wider picture, and more importantly, that participants need more practical forms of assistance than we have imagined. When helping mothers on non-research related matters, whether it was helping them secure support for their child or arranging childcare whilst they fulfilled their other responsibilities, I was able to enrich our relationship and leave the field knowing I had engaged ethically. This was a difficult task for an over-worked postgraduate student / researcher / mother to balance, and it leaves

some interesting questions about the feminist obligations of Doctoral researchers such as myself and how our own personal and professional limitations affect our commitment to achieving feminist goals. It magnifies the imperfect contexts in which we embrace and put into practice feminist methodology.

Perhaps the biggest challenge of ‘doing feminism’ was adapting a theoretical lens that addressed the goals of social justice. A crystallised image exists within academic and media discourse of British South Asian Muslim women being passive and oppressed by their circumstances who need rescuing by outsiders, and who are disinterested in their child’s educational experiences and overall outcomes. By utilising the Intersectional Framework (Weber 2001), mothers in my research not only exposed this imagery as false but also as stigmatising and disabling to their experiences. My participants acted as their own agents of change, rescuing and enabling themselves by recognising those positionalities that afforded them better experiences of their child’s SEND, whilst disregarding those that disabled them. I posit that this is one of the key strengths of engaging with feminist epistemology and methodology within educational research.

In adopting a feminist theoretical stance and methodology within my research, I realised that there are no rigid guidelines that feminist researchers can apply in the field. However, if one is truly committed to feminist principles, then the researcher can adapt research methods to the field which empower both the researcher and the researched. In the process of ‘doing’ research, I ensured that my actions were underpinned by my strong ethical obligations to my participants; only then did I feel that I was progressing as feminist researcher, researching women from my own community whilst ensuring a safe space for their voices to address their concerns. Whilst feminist methodology is still evolving, it is central to making educational research inclusive and representative of all

minority groups, and in challenging the existing educational discourse to become more critical of its normative assumptions.

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